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RESEARCH PAPER

Social participation after successful kidney transplantation

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Abstract

Purpose. To explore and describe the degree of social participation after kidney transplantation and to examine associated factors.

Method. A cross-sectional study on 239 adult patients 1–7.3 years after kidney transplantation was performed via in-home interviews on participation in obligatory activities (i.e., employment, education, household tasks) and leisure activities (volunteer work, assisting others, recreation, sports, clubs/associations, socializing, going out).

Results. Kidney transplantation patients had a lower educational level, spent less time on obligatory activities, had part-time jobs more often, and participated less in sports compared to a control group from the general population. No difference was found in socializing, church attendance, volunteer work and going out. Multivariate regression analysis showed a negative association of age and a positive association of educational status and time since transplantation with obligatory participation. Multivariate logistic regression showed positive associations of education and time since transplantation with volunteer work; age was negatively and education positively associated with sports and going out, whereas living arrangement was also associated with going out.

Conclusions. Although kidney transplantation patients participate less in employment and sports, they do participate in household tasks, volunteer work, going out, socializing and other leisure activities. Participation is associated with factors as age, educational status and time since transplantation.

Keywords: Social participation, employment, household tasks, leisure activities, sports, kidney transplantation

Introduction

The incidence of renal replacement therapy (RRT) for end-stage renal disease (ESRD) rose rapidly in the European countries from 79.4 per million population (pmp) in 1990–1991 to 117.1 in 1998–1999 [1]. A worldwide study of 120 countries revealed an increase of 7% in treated ESRD patients between 2000 and 2001. The majority of patients were treated by dialysis and 23% received a donor organ [2]. It is expected that the number of people living with ESRD will further increase [3]. Treatment with dialysis can be accompanied by symptoms as physical and mental fatigue, reduced functional capacity and reduced cognitive performance, which

may lead to inability to perform in social roles [4–7]. Once on dialysis patients are evaluated for eligibility for kidney transplantation, which nowadays has become a routine procedure and treatment of choice for ESRD, as it is associated with a better prognosis [8,9].

Transplantation alters daily life of patients and requires adjustment and adaptation. After transplantation patients have to comply with a strict therapeutic regime of medication and hospital visits, mostly accompanied by feelings of uncertainty due to the fear of rejection [10]. Despite these worries a variety of studies showed a satisfactory quality of life after transplantation [11–14]. Criticism on methodology used in those studies however identified

shortcomings of quality of life research, questioning the results and optimistic outlook on life after transplantation [15].

A new approach for studying life after transplantation is the concept of participation introduced by the World Health Organization and outlined in the International Classification of Functioning, Disability and Health (ICF) [16,17]. Participation is defined as 'involvement in life situations' and represents the societal perspective of functioning. Dysfunctioning is expressed as activity limitation and restriction in participation, assessed as a variety of role behaviours relevant to everyday life. Besides basic self-care activities this includes more advanced and complex social activities such as work and leisure activities. A recent systematic review on participation in society after kidney transplantation demonstrated that only few previous studies assessed actual performance of activities or behaviour connected to participation [18]. Most studies focused on employment status or return to work. In three studies employment was the outcome measure of interest [19–21], while other studies reported on employment as explanatory variable or covariate in relation to outcome variables such as (health-related) quality of life [22–24]. In addition to employment only two studies briefly examined and presented data on other aspects of social participation, such as vacation and taking up new recreational activities [25,26]. Results on prognostic demographic and clinical factors were inconsistent. Because of the moderate validity and heterogeneity of the reviewed studies, a clear conclusion on the degree of social participation could not be drawn. Therefore it can be concluded that current knowledge of the degree of social participation after kidney transplantation is limited, whereas recently the importance of examining 'normal' life after transplantation has been emphasized [27].

For these reasons the purpose of the present study was to explore and describe the degree of social participation after kidney transplantation. Patients who are no longer in need of dialysis as a consequence save time and energy every day. This poses the question how people utilize this time and energy. Are they able to participate in a socially and economically active and productive life again? Because of the sparse data on activities other than employment, the present study has focused on household tasks, education, social and leisure activities, next to employment. To evaluate the degree of social participation of kidney transplantation patients we made a comparison with a control group from the general population. Additionally, potential explanatory non-disease factors such as demographic and social characteristics were examined, since previous research on other populations

showed an association between these factors and participation [28,29].

Methods

Study population

The study population in this cross-sectional study consisted of patients who visited the outpatient clinic of the Transplantation Centre of the University Medical Centre Groningen for follow-up after primary kidney transplantation. Patients who were transplanted between January 1, 1996, and December 31, 2001, were eligible subject to having had their transplantation at least one year preliminary to entrance of the study, being 18 years or older at follow-up and having a functioning allograft. Combined transplantation patients (i.e., kidney/pancreas or kidney/liver) and retransplantation patients were excluded as were patients unable to understand Dutch. Patients with a poor mental or physical health status were excluded as well. Dutch-speaking patients with a visual impairment were assisted in completing the questionnaires. Patients were enrolled between May 2002 and March 2003. The study was approved by the Medical Ethics Review Committee of the University Medical Centre Groningen. After receiving oral and written information about the study, patients signed informed consent.

Control group

The Time Use Survey (TUS) is a survey among a random national sample, first conducted in 1975 and repeated at five-yearly intervals, performed by the Social and Cultural Planning office of The Netherlands (SCP) [30]. This survey uses time-diaries and in-home interviews. Data from these interviews were used to make a comparison with the present study, because of the similarity of data collection methodology. Since the concept of social participation is only partly analogous to the concept of time-use, a selection of variables were compared. For matching purposes we applied geographical restriction according to the provinces of residence of the study group. This resulted in 634 potential controls of the original dataset of TUS 2000 ($n = 1813$). Then, study participants were matched for age with a tolerance of two years, and for gender.

Data collection

Data for the present study were collected by interview at the participant's homes. The interview schedule developed for this study was assessed on face and content validity by a panel consisting of

patients ($n = 2$), researchers experienced in rehabilitation ($n = 2$) or quality of life research ($n = 2$), nurse specialist ($n = 1$), nephrologist ($n = 1$) and social research methodologists ($n = 2$). A pilot study among ten kidney transplantation patients was executed and minor revisions were made. The interviews were performed by a team of seven experienced and skilled interviewers of the Northern Centre for Healthcare research. The first in-home interview of each interviewer was tape recorded and listened to by the first author (SFM) and discussed afterwards. The interviewers attended training sessions aimed to reduce measurement error through enhancement of standardization of interview technique.

Measurement of social participation

Social participation was operationalized as patient's actual involvement in society as a result of interaction between individuals or social functioning in a group. Social participation was divided in activities with obligatory characteristics and leisure activities.

Obligatory participation. Obligatory activities were connected to expected roles, i.e., employment, education, household tasks. The number of hours per week spent on employment, education and household tasks were added, yielding a continuous score (range 4–70). Subsequently this score was categorized in three groups (≤ 16 hours, 17–32 hours, > 32 hours). The degree or intensity of social participation of patients who scored ≤ 16 h was classified as low and of patients scoring > 32 h as high. Employment was classified as full-time (≥ 30 h/week), part-time (12–29 h/week) and as 'minor jobs' (1–11 h/week).

Leisure participation. Leisure activities comprised participation in:

- (a) Volunteer work (yes/no), defined as unpaid work in organized associations performed on the volunteer's own free will, benefiting the community or others;
- (b) Assisting others (yes/no), defined as informal assistance of others outside the participant's own home;
- (c) Recreational activities or hobbies for pleasure. The frequency of 36 hobbies was assessed on a scale of 0 (never) through 5 (daily). Hobbies were also assessed for social interaction, i.e., if these hobbies were engaged in company with others or on one's own. Reported solitary hobbies where interaction with others is obvious such as, e.g., shopping, travelling, taking a course were also included. Addition of frequencies of

all interactional hobbies resulted in a total score, which was dichotomized due to a skewed distribution. Patients engaging more than once a week in recreational activities were classified as frequently participating (yes/no);

- (d) Sports (yes/no) that are practised in company with others. Reported solitary sports such as, e.g., going to a fitness centre and public swimming pool were also considered interactional, whereas yoga and exercise bicycling at home were not. Walking and cycling as means of getting about or commuting were not considered as sporting activities;
- (e) Involvement in clubs or associations (yes/no), with active membership defined as visiting meetings, being organizer or committee member etc. Church attendance of patients affiliated with a religion was also included;
- (f) Socializing with relatives (other than the participant's own family) and friends or acquaintances, defined as personal meetings as well as contacts by telephone, mail or e-mail. Frequency was assessed on a scale of 0 (never) through 3 ($> 1 \times$ /week) for relatives and friends or acquaintances separately, and finally added to a total score, which was dichotomized due to a skewed distribution. Patients who socialized more than once a week with family, friends or acquaintances were classified as frequently participating (yes/no);
- (g) Going out for entertainment to public places (café, restaurant, discotheque, club etc.) or cultural places (museum, exhibition, theatre, cinema etc.). Frequency was assessed on a scale of 0 (never) through 3 ($> 1 \times$ /week) for public and cultural places separately, and finally added to a total score, which was dichotomized due to a skewed distribution. Patients going out once every two weeks or more were classified as frequently participating (yes/no).

Furthermore, the diversity of leisure activities was measured representing the width of participation in leisure time. For this purpose the scores on the seven dichotomous leisure activities were summed to obtain a total diversity score (range 0–7).

Explanatory variables

Age, measured in years at the time of the interview, was not categorized because no relevant cut-off point for social participation is known. Considering

employment, for example, official retirement in The Netherlands starts at the age of 65 but more often at an earlier age. Living arrangement is defined as: (i) living with a partner without children; (ii) a parent living with one or more children at home (one- and two-parent family); (iii) living alone; (iv) living with parents. Educational status was defined as the highest attained level of education and classified as: (a) primary education; (b) lower secondary education; (c) upper secondary education; and (d) tertiary education [31]. Time since transplantation was measured as time in years between date of transplantation and date of interview.

Statistical analysis

Differences between study and control group in demographic characteristics and dichotomous outcome variables were analysed by the Chi-square test. Time spent on employment, household tasks and total obligatory time was tested by the Mann-Whitney test due to a skewed distribution. P value < 0.05 (two-sided) was considered statistically significant. The association between obligatory and leisure activities was analysed by the Chi-square test and the test for trend if appropriate, and by the Kruskal Wallis test (diversity of leisure activities). Univariate and multivariate regression analysis was applied to examine the association between explanatory variables, and total time spent on obligatory activities and diversity of leisure activities. For selection of variables first the factor with the strongest association was entered, followed by the next strongest, until all associated variables were entered in the model, if $p < 0.05$. Interactions between factors were tested if relevant, except interactions with living arrangement because of the small subgroups. Similarly, univariate and multivariate logistic regression analysis was applied to examine the association between explanatory variables and participation in leisure activities. Differences between study and control group in obligatory and leisure participation were adjusted for age and education. Data analysis was performed using the statistical software package SPSS, version 12.0.2 (SPSS, Inc., Chicago).

Results

Study participants and control group

Of the initial cohort ($n = 421$) of patients with primary kidney transplantation between 1996 and 2001, 9% had died at the time of the study, 11% had renal graft failure and 1% had moved elsewhere. Of the remaining 334, 23 patients were

found to be ineligible because of mental retardation ($n = 5$), inadequate mastery of Dutch ($n = 5$) and miscellaneous reasons ($n = 4$). In addition, nine patients with severe physical health problems (i.e., difficulty with speech due to cerebrovascular disease, disability requiring living in a nursing home, chronic malaise/exhaustion) and mental health problems (i.e., current depression requiring treatment, unstable psychiatric history) were excluded. Of the 311 patients approached for participation in this study 249 (80%) agreed to participate. Ten patients participated in the pilot study, so 239 patients were enrolled in this study (57% male, 43% female).

Mean age was 50.3 years (range 19–71) and mean time since transplantation 3.8 years (range 1–7.3). Demographic characteristics of the study group and the matched control group from the general population were similar, except for a difference in educational status (Table I).

Participation in obligatory and leisure activities

Fifty-two per cent of the patients of working age (< 65 year; $n = 210$) had a paid job (Table II). Sixty-eight per cent of the patients without a paid job ($n = 100$) reported work disability as the reason for not being employed. Four patients were full-time students. The total time spent weekly on employment, education and household tasks showed that 36% of the patients scored ≤ 16 h, indicating a low

Table I. Demographic and clinical characteristics of the study group, and the control group from the general population ($n = 239$).

Characteristics	Study group $n = 239$		Control group $n = 239$		p -value
Age—yr (SD)	50.3	(12.7)	50.3	(12.8)	Matched
Sex					Matched
Male	137	(57.3)	137	(57.3)	0.25
Female	102	(42.7)	102	(42.7)	
Living arrangement					
Cohabitation	117	(49.0)	100	(41.8)	<0.01
Parent with child	68	(28.5)	87	(36.4)	
Living alone	43	(18.0)	44	(18.4)	
Living with parents	11	(4.6)	8	(3.3)	
Educational status					<0.01
Primary	45	(18.8)	20	(8.4)	
Lower secondary	89	(37.2)	89	(37.2)	
Upper secondary	69	(28.9)	67	(28.0)	
Tertiary	36	(15.1)	63	(26.4)	0.70
Country of origin					
Netherlands	224	(93.7)	226	(94.6)	
Other countries	15	(6.3)	13	(5.4)	
Time since Tx—yr (SD)	3.8	(1.9)			

Numbers are: n (%); Tx, transplantation.

degree of participation in obligatory activities, whereas 39% had a high degree of participation (> 32 h/week).

With regard to participation in leisure activities (Table III) 40% of the patients were doing volunteer work and 38% reported assisting others. A quarter of the patients practised sports. A majority of the study group was actively involved in clubs and associations (64%) and frequently performed recreational activities (53%). Some 59% reported frequent socializing, more often with family than with friends or acquaintances. Going out to public places was reported by 42%, more often to public than to

cultural places. The mean diversity of leisure activities was 3.2 (range 0–7); 3% did not participate in any of the leisure activities.

Obligatory participation was stratified in three categories of intensity or hours spent weekly to examine the interrelation between obligatory and leisure activities (Table III). The results indicate that the subgroup with the fewest hours of obligatory participation (≤ 16 h) had the lowest participation rate in sports, by contrast the highest in assisting others and volunteer work. The middle group (17–32 h) had the lowest participation rate in volunteer work and going out, and overall had a less diverse leisure pattern. The subgroup participating > 32 h had the highest participation rate in sports and going out, and was doing volunteer work as well, but on the contrary was less involved in the assistance of others.

Table II. Participation in employment, education and household tasks, and total time spent on obligatory activities a week of the study group and the control group ($n = 239$).

	Study group $n = 239$		Control group $n = 239$		p -value
Employment*					
Paid job	110/210	(52)	123/207	(59)	0.15
Employed participants—					
Full-time	60	(55)	85	(69)	
Part-time	40	(36)	29	(24)	
Minor jobs**	10	(9)	9	(7)	
Median hrs	32		36		0.02
Full-time education*	4/210	(2)	8/207	(4)	**
Household tasks					
< 8 h/week	82	(34)	87	(36)	
8–18 h/week	103	(43)	89	(37)	
> 18 h/week	54	(23)	63	(26)	
Median hrs	10		10		0.88
Total obligatory time					
≤ 16 h/week	86	(36)	71	(30)	
17–32 h/week	61	(26)	51	(21)	
> 32 h/week	92	(39)	117	(49)	
Median hrs	23		32		0.01

Numbers are: n (%); * < 65 yr; **Not tested on statistical significance due to small sample size; Due to rounding off the sum of percentages can be $<$ or $>$ than 100%.

Comparison with control group

Comparison of participation in obligatory activities between study and control group showed no difference in proportion of participants having a paid job ($p = 0.15$; Table II). However, the median hours spent on employment by the study group was significantly lower ($p = 0.02$), indicating that kidney transplantation patients worked less full-time and more often had part-time or minor jobs. There was no difference in household tasks. In total, kidney transplantation patients spent less time on obligatory activities compared to the control group ($p = 0.01$).

Comparison of participation in leisure activities (no table) demonstrated a lag in sporting activity for kidney transplantation patients as 51% of the control group exercised ($p < 0.001$). With reference to socializing we compared having dinner with family, friends or acquaintances regularly ($\geq 1 \times / 2$ weeks) which showed no difference ($p = 0.41$). Comparison of church attendance in case of affiliation with a religion did not differ ($p = 0.07$). No difference was found in participation in volunteer work (control

Table III. Participation in leisure activities by categories of obligatory participation of the study group ($n = 239$).

	Total group		≤ 16 h $n = 86$		17–32 h $n = 61$		> 32 h $n = 92$		p -value
	n	%	n	%	n	%	n	%	
Leisure activities—no. (%)									
Volunteer work	95	(40)	39	(45)	15	(25)	41	(45)	0.02
Assisting others	91	(38)	40	(47)	22	(36)	29	(32)	0.04
Sporting activity	63	(26)	16	(19)	13	(21)	34	(37)	< 0.01
Involvement in clubs/associations	152	(64)	58	(67)	36	(59)	58	(63)	0.57
Recreational activity ^a	126	(53)	52	(60)	28	(46)	46	(50)	0.18
Socializing (relatives/friends) ^a	140	(59)	53	(62)	32	(52)	55	(60)	0.52
Going out (public, cultural) ^b	100	(42)	32	(37)	19	(31)	49	(53)	0.01
Diversity—mean (SD)	3.2	(1.6)	3.4	(1.6)	2.7	(1.4)	3.4	(1.8)	0.02

^a $> 1 \times / \text{week}$; ^b $\geq 1 \times / 2$ weeks.

group 44%, $p = 0.40$) or frequently going out (control group 44%, $p = 0.64$).

Predictors of obligatory participation

Results of univariate regression analysis of total hours spent on obligatory activities on explanatory variables (Table IV) showed that age was a significant predictor ($B -0.62$; 95% CI: -0.76 to -0.48) indicating a lower level of obligatory participation with advanced age. Considering gender, women appeared to participate less in obligatory activities, although gender was not a significant predictor ($B -3.72$; 95% CI: -7.80 to 0.36).

Analysis in more detail showed that men of working age were more frequently (63%) employed than women (37%; $p < 0.001$). Among those with a paid job, men also spent more time on employment (median 36 h) than women (median 20 h; $p < 0.001$). In contrast, women spent more time on household tasks (median 15 h) than men (median 4 h; $p < 0.001$). As a result there was no difference in total hours spent on obligatory activities between men (median 30 h) and women (median 22 h; $p = 0.15$). Living arrangement showed more participation for patients living with children compared to the reference group (cohabitation without children). There was a difference in education resulting in a higher level of obligatory participation for patients with upper secondary ($B 9.32$; 95% CI: $3.51 - 15.13$) or tertiary education ($B 12.98$; 95% CI: $6.20 - 19.76$), compared to the reference group with only primary education.

Multivariate analysis resulted in a model ($F 19.72$; $p < 0.001$; $R^2 0.30$) with age, education and time since transplantation as significant predictors

(Table IV). The standardized regression coefficients showed that age mostly affected the outcome of obligatory participation. There were no significant interaction effects between predictors.

Predictors of leisure participation

Results of univariate logistic regression analyses with each of the leisure activities as dichotomous outcome variable showed no association between the explanatory variables and four leisure activities, i.e., assisting others, recreation, socializing and involvement in clubs or associations (Table V).

Significant associations were found for going out, sports and volunteer work. Age was associated with going out (OR 0.95; 95% CI: $0.93 - 0.97$) and sports (OR 0.97; 95% CI: $0.95 - 0.99$), indicating less activity with advanced age. Moreover, gender was associated with going out indicating that females were less going out. The association with living arrangement showed that patients living with their parents were more frequently going out in comparison to the reference group (cohabitation without children). Association of education with volunteer work, going out and sporting activity showed more participation in these activities for patients with a higher education in comparison with the reference group (primary education). Time since transplantation was only associated with volunteer work.

Multivariate analysis of predictors of volunteer work and sports respectively did not change the ORs of education and time since transplantation considerably (Table VI). Multivariate analysis of going out showed an effect for age, living arrangement and education, whereas gender was not significant anymore. There were no significant interaction effects

Table IV. Univariate and multivariate regression of total time spent on obligatory activities on demographic and clinical characteristics of the study group ($n = 239$).

	Univariate			Multivariate			
	<i>B</i>	CI		β	<i>B</i>	CI	
Age	-0.62	-0.76	-0.48	-0.48	-0.59	-0.73	-0.46
Sex							
Male (reference)							
Female	-3.72	-7.80	0.36				
Living arrangement							
Cohabitation (reference)							
Parent living with children	6.47	1.75	11.18				
Living alone	5.01	-0.51	10.52				
Living with parents	7.21	-2.54	16.96				
Educational status							
Primary (reference)							
Lower secondary	4.16	-1.38	9.71	0.02	0.65	-4.28	5.58
Upper secondary	9.32	3.51	15.13	0.11	3.75	-1.49	9.00
Tertiary	12.98	6.20	19.76	0.20	8.69	2.68	14.71
Time since transplantation	0.94	-0.14	2.02	0.12	0.98	0.06	1.91

B, regression coefficient; CI, confidence interval (95%); β , standardized regression coefficient.

Table V. Univariate logistic regression of seven types of leisure activities on demographic and clinical characteristics of the study group ($n = 239$).

	Volunteer work		Assisting others		Recreation		Socializing		Going out		Sporting		Involvement in clubs	
	OR	CI	OR	CI	OR	CI	OR	CI	OR	CI	OR	CI	OR	CI
Age	0.99	0.97–1.01	1.00	0.98–1.02	0.99	0.97–1.01	0.99	0.97–1.01	0.95	0.93–0.97**	0.97	0.95–0.99*	1.01	0.99–1.03
Sex														
Male (reference)														
Female	0.62	0.37–1.06	1.17	0.69–1.98	1.34	0.80–2.24	1.26	0.75–2.12	0.54	0.32–0.92*	1.01	0.57–1.81	0.70	0.41–1.19
Living arrangement														
Cohabitation (reference)														
Parent living with children	1.19	0.65–2.19	0.59	0.31–1.09	0.96	0.52–1.74	0.94	0.51–1.71	0.69	0.37–1.30	1.88	0.96–3.67	2.09	1.08–4.04 ⁺
Living alone	0.95	0.46–1.95	0.77	0.37–1.57	0.52	0.26–1.07	1.17	0.57–2.41	1.78	0.88–3.59	1.43	0.64–3.17	1.06	0.52–2.17
Living with parents	1.33	0.38–4.63	0.49	0.12–1.92	1.40	0.39–5.04	0.58	0.17–2.01	15.44	1.91–124.64*	1.38	0.34–5.59	0.84	0.24–2.89
Educational status														
Primary (reference)														
Lower secondary	2.59	1.11–6.04*	0.89	0.43–1.84	1.07	0.52–2.20	2.16	1.04–4.50 ⁺	1.14	0.51–2.53	1.52	0.62–3.75	1.56	0.75–3.23
Upper secondary	4.12	1.73–9.83**	0.88	0.41–1.89	1.21	0.57–2.57	1.44	0.68–3.07	3.58	1.58–8.07**	1.29	0.50–3.34	1.64	0.76–3.53
Tertiary	3.20	1.20–8.55*	0.53	0.21–1.35	0.50	0.20–1.21	1.05	0.44–2.51	4.87	1.89–12.6**	4.63	1.70–12.6**	2.28	0.89–5.80
Time since transplantation	1.17	1.02–1.35*	1.08	0.94–1.24	0.92	0.80–1.05	1.02	0.89–1.17	1.03	0.90–1.19	1.11	0.95–1.30	1.05	0.91–1.21

OR, Odds ratio; CI, confidence interval (95%); * $p < 0.05$; ** $p < 0.01$; ⁺Wald statistic not significant.

between age and education, whereas interaction between age and living arrangement was not tested due to small subgroups.

Univariate regression analysis of diversity of leisure activities (no table) showed an association with age ($B = -0.02$; 95% CI: -0.04 to -0.01), indicating a less diverse leisure pattern with advanced age. Association with education showed more diversity for patients with upper secondary ($B = 0.87$; 95% CI: 0.26 – 1.49) or tertiary education ($B = 0.82$; 95% CI: 0.10 – 1.54), compared to the reference group. Gender, living arrangement and time since transplantation were not associated with diversity. Education, in addition to age, as explanatory variable in a multivariate regression analysis did not result in a significant model.

Comparison with control group after adjustment for covariates

To assess the difference between study and control group after adjusting for demographic characteristics a regression analysis on obligatory participation was performed ($n = 478$, Table VII). Univariate regression analysis showed a higher level of obligatory participation for the control group compared to the reference group of kidney transplantation patients ($B = 3.91$; 95% CI: 1.04 – 6.79).

After adjustment for age and educational level this difference was still significant ($B = 3.35$; 95% CI: 0.91 – 5.79). There was an indication of interaction between age and group (study group as reference) although not significant ($B = -0.17$; 95% CI: -0.36 to 0.02). With respect to participation in sports (no table) adjustment for age and education yielded an odds ratio of 2.37 (95% CI: 1.66 – 3.50) for the control group, indicating more frequent participation in sports compared to kidney transplantation patients. There was no significant interaction.

Discussion

The aim of this study has been to describe the degree of social participation and to examine explanatory factors. The present study is to our knowledge the first long-term study (1–7 years) after kidney transplantation which assesses participation in society from a comprehensive perspective. Besides participation in employment, education and household tasks, we defined participation in leisure activities as a relevant outcome measure of transplantation, this in contrast with global, overall perceptions of quality of life. These overall perceptions are often as high as those of healthy persons, which appears to be in contradiction with the more modest benefits of transplantation when domains of quality of life are studied separately [32].

Table VI. Multivariate logistic regression of volunteer work, sporting activity and going out on demographic and clinical characteristics of the study group ($n = 239$).

	Volunteer work		Sporting activity		Going out	
	OR	CI	OR	CI	OR	CI
Age			0.97	0.95–0.99*	0.95	0.92–0.98**
Sex						
Male (reference)						
Female						
Living arrangement						
Cohabitation (reference)						
Parent living with children					0.31	0.14–0.69**
Living alone					1.39	0.60–3.23
Living with parents					5.37	0.58–49.28
Educational status						
Primary (reference)						
Lower sec.	2.43	1.03–5.69*	1.31	0.52–3.28	1.00	0.41–2.41
Upper sec.	4.03	1.68–9.67**	0.99	0.37–2.66	2.92	1.19–7.18*
Tertiary	3.05	1.13–8.21*	3.95	1.42–10.97**	6.92	2.39–20.10**
Time since transplantation	1.16	1.01–1.34*				

OR, Odds ratio; CI, confidence interval (95%); * $p < 0.05$; ** $p < 0.01$.

Table VII. Univariate and multivariate regression of total time spent on obligatory activities on demographic characteristics of the study and the control group ($n = 478$).

	Univariate			Multivariate			
	<i>B</i>	CI		β	<i>B</i>	CI	
Group							
Study group (reference)	3.91	1.04	6.79	0.10	3.35	0.91	5.79
Age	–0.69	–0.78	–0.59	–0.52	–0.66	–0.76	–0.56
Sex							
Male (reference)							
Female	–3.03	–5.95	–0.11				
Living arrangement							
Cohabitation (reference)							
Parent living with children	8.22	5.00	11.44				
Living alone	7.04	3.15	10.93				
Living with parents	13.96	6.63	21.28				
Educational status							
Primary (reference)							
Lower secondary	7.11	2.65	11.56	0.06	1.87	–2.02	5.75
Upper secondary	12.21	7.57	16.85	0.12	4.20	0.09	8.32
Tertiary	11.57	6.66	16.48	0.14	5.53	1.21	9.85

B, regression coefficient; CI, confidence interval (95%); β , standardized regression coefficient.

Some 36% of the study group spent 16 h or less weekly on obligatory activities, which indicates a low degree of obligatory participation. This group also had the lowest participation rate in sports, but was contrarily more involved in volunteer work and assisting others. A higher proportion of participation in clubs or associations, recreation and socializing however was not statistically significant. These results suggest that leisure time activities serve as a kind of meaningful substitute for decreased time spent on obligatory activities. The group which spends 17–32 h weekly on obligatory activities is significantly less involved in leisure activities, although still 25% is involved in volunteer work. A

possible explanation is that available time and perhaps available energy too are more likely spent on obligatory activities at a disadvantage of leisure activities. The subgroup spending most time on obligatory activities (>32 h) was more often involved in sporting activity, going out and volunteer work. Obviously this group had enough energy for leisure activities in addition to obligatory activities. The participation in volunteer work demonstrates the desire of patients to interact with others in a beneficial manner and moreover their ability and initiative to do so.

A total of 52% ($n = 110$) of the study group was employed which may give the impression that

vocational rehabilitation of patients after transplantation was successful. However, 48% ($n = 53$) of the patients with a paid job also received additional social security benefits due to disability. As a consequence only 57 patients (27%) of working age in the study group were capable of performing in a paid job without the support of social services. Moreover, disability was also the main reason for patients not being employed which demonstrates the high prevalence of work disability in this population. These results however apply to the situation in The Netherlands which has worldwide the highest number of registered work disabled according to the Work Disability Insurance Act [33]. In general, comparison of results on employment is hindered by the variety of applied definitions (e.g., full-time, part-time), classifications (e.g., including students and homemakers as employed) and differences in social security legislation between countries.

As mentioned before, previous research on participation in activities other than employment is sparse. Results with respect to sports are heterogeneous as participation rates of 15% [34] and 74% [35] were found. A change in terms of more frequent participation in social life in general was found in 83% of patients after transplantation, and 70% did go on holiday [25]. Baines et al. (2002) found improvement in social interaction and relationships after psychotherapy [26].

Comparison with the control group showed that kidney transplantation patients participate less in paid work, especially work less full-time, which is not surprising considering the prevalence of work disability. Reduction of working hours can be considered as a type of work adjustment [36], in this study reflected as the percentage of patients with a part-time or minor job. This study shows the importance of detailed measurement of employment in weekly working hours, instead of reporting merely the percentage of patients with or without a paid job. In contrast with employment no difference in time spent on household tasks between study and control group was found. An assumption was that when less time is spent on paid work as a consequence more time is left for other commitments such as household tasks; however our results did not support this principle of substitution [37].

Comparison of participation in leisure activities with the control group showed that kidney transplantation patients were less involved in sports. A recent study found a decreased exercise capacity and muscle strength in kidney transplantation patients compared to healthy controls [38], which may be connected with this result. As no differences were found with respect to other leisure activities, we conclude that patients in particular are impaired in activities characterized by commitments (i.e., em-

ployment) as well as activities which require a certain level of physical health or stamina (i.e., employment, sports). On the other hand, leisure activities may be more accessible. These are on average characterized by flexibility, little or no time pressure or pressure to achieve demanding objectives, and provide more opportunities for individual choices or adaptations.

The difference in educational level between kidney transplantation patients and the control group was an unexpected finding, in spite of matching for age and gender, and geographical restriction. A Dutch long-term follow-up study, which evaluated late physical, social and psychological effect of renal insufficiency in children, found that educational attainment of patients with a functioning allograft was significantly lower than the age-matched (22–44 yrs) general population [39]. Diagnosis and treatment of end-stage renal disease in childhood appears to be associated with a lower educational level, which was also found in another study [40]. The majority of participants in the present study however were diagnosed with end-stage renal disease in adult life. A study among Dutch patients with chronic diseases also demonstrated a low educational level, 18% had primary education and 15% tertiary education [41]. These figures are in line with our findings and suggest that not only kidney transplantation patients but chronic diseased patients in general are less well educated. This so-called socio-economic inequality in health is extensively described [42–44]. A recent study on specific diseases related to inequalities in education however found no differences for the disease group of kidney diseases [45]. The author's remark that the data on the chronic diseases were based on self-reports. Moreover, the inclusion of kidney stones in the kidney disease group questions the applicability of the findings to the present study.

The present study showed the association between non-disease factors, such as age and educational level, and social participation. This association was also found in the general population [30]. We found no association for gender which can be explained by the operationalization of participation in obligatory activities, i.e., the summation of time spent on employment, education and household tasks. Although women spent less time on employment, this was counterbalanced by the number of hours spent on household tasks. The multivariate model with age, education and time since transplantation as significant factors explained only 30% of the variance of obligatory participation. Apparently other factors such as transplantation-related, psycho-social or environmental factors may also affect social participation.

The examination of social participation long-term after primary kidney transplantation in a homogeneous study population of substantial size is one of the strengths of the present study. Moreover, the

control group from the general population gives the opportunity to parallel the degree of social participation. The response rate of 80% in addition is considered as satisfactory. However, there are some limitations. The exclusion of patients with a poor health status may have resulted in an overestimation of social participation, although this concerned only nine patients. The cross-sectional design limits inferences of causality and as a consequence identified associations of explanatory factors must not be misconceived as causal factors of social participation. Furthermore, we used an internally developed interview schedule to measure social participation in the absence of an appropriate questionnaire at the time when preparations were made for data-collection. Existing measurement scales as the Life Habits Questionnaire [46,47], developed to study subjects with physical impairments, did not correspond with the study population of the present study and would probably have resulted in ceiling effects [48]. Likewise, the questionnaire Impact on Participation and Autonomy [49] assessed patient-perceived participation, which did not correspond with the objective to measure actual participation. Diversity of leisure activities merely represents the width of participation in the seven defined leisure activities, which is not equivalent to the intensity or amount of time spent on these activities. Consequently, intensive participation in merely one of these leisure activities will still result in a low diversity score. A disadvantage of utilizing existing databases, in our study the Time Use Survey, is that available variables not completely correspond with the variables under study. As a result we compared church attendance as indicator of involvement in clubs and associations, and having dinner with family, friends or acquaintances as indicator of socializing. Furthermore, we were unable to compare two types of leisure activities, i.e., assisting others and recreation. Because of these restrictions the comparison of leisure activities between study and control group is not as complete as the comparison of obligatory activities.

To conclude, the present study demonstrated that although patients are less well educated and participate less in employment and sports, they do participate in activities such as household tasks, volunteer work, socializing and other leisure activities. Age and educational level were associated with participation in both obligatory and leisure activities, whereas time since transplantation was associated with participation in obligatory activities and volunteer work. The associations between these explanatory factors and social participation correspond with those of the general population. As a result, no specific subgroups of kidney transplantation patients at risk for decreased social participation can be identified, in addition to the pattern also seen in the

general population. The results of the present study can be regarded as the first step to fill in the gap of knowledge with respect to participation in society of patients after kidney transplantation.

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